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Chapter 2

HIV Infection — A Sociological Approach to the Prevention of the HIV Pandemic

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Additional information is available at the end of the chapter

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1. Introduction

> "The first step [in transforming] reality is [usually] learning to see it [from] a new perspective (and being capable of showing it to others [in] this light)." *Jorge Riechmann*

Despite the fact that over three decades have passed since the first recorded case of AIDS in 1981, many questions remain unanswered regarding the HIV pandemic: how did HIV originate? When will an effective vaccine be available? How do strategies and measures for prevention need to be designed and implemented?

Currently, the prevention and elimination of HIV is one of the major challenges for public health worldwide. The HIV pandemic constitutes a social problem of great magnitude. It is a complex social phenomenon that is difficult to address. Thus, in order to study its complexity, it is necessary to adopt an interdisciplinary approach. In this sense, the sociological discipline and in particular, the sociology of health, is an important tool for the study and understanding of HIV. The general purpose of this chapter is to reveal and justify the relevance of integrating a sociological perspective to the study of HIV prevention. Firstly, the extent and magnitude of the epidemic on a global scale is described. Secondly, sociological theories and methodologies that might be usefully applied in the field of HIV prevention and treatment are presented and justified. Finally, conclusions are drawn considering a number of relevant and pertinent analytical elements that are crucial to the development of HIV prevention policies.

2. The globalization of the pandemic

At present, there is evidence that globalization has affected health care in a variety of ways. In this sense, the majority of the most prestigious institutions and organizations in the field of public health have become standard-bearers for the concept of global health. As such, the concept of global health is a consequence of the process of globalization. The definition of global health pursues equity in health matters worldwide; it is a priority objective for the international technocratic agenda [1].

The globalization process, with its multiple dimensions (economic, political, social, ecological, etc.), has had a significant impact on global health. For instance, economic globalization through the internationalization of trade and the communications revolution has resulted in the globalization of risks and of certain diseases [2]. In addition, ecological globalization, alongside the environmental and ecological changes it entails, has also had an effect on health [3]. This can be illustrated by the following: water deprivation due to scarcity implies major health risks; air pollution has caused an increase in respiratory diseases; climatic change with its ensuing extreme temperature variations affect cardiovascular diseases and the depletion of the ozone layer has increased the incidence of skin cancer [4]. On the other hand, the interdependence generated between governments and transnational problems, characteristic of political globalization, have shifted power away from the State in favour of the creation of international institutions. Thus, the World Health Organisation is today the largest exponent of health, while UNAIDS serves this purpose in the case of HIV.

Consequently, social phenomena such as health tourism, the migration of health professionals to developed countries, the existence of global risks, the resurgence of diseases that had previously been limited (such as tuberculosis) in developed countries and the global emergence of infectious diseases (avian influenza, HIV, etc.) are greatly related to the globalisation process. Specifically, globalisation has important repercussions for emerging infectious diseases: "Since the 1970s, newly emerging diseases have been identified at the unprecedented rate of one or more per year. There are now at least 40 diseases that were unknown a generation ago" [5].

In general terms, the relationship established between globalization and global health is not a positive one. However, it is worth noting that globalization has also had a positive impact on certain aspects of global health, given that it offers opportunities and provides improvements related to population health. For instance, globally, the total poverty rate has declined from 20% to 5% over the past 25 years [6]. Globalization, to the extent that it produces greater economic growth, generally involves improvements in population health. For instance, globalization has resulted in better health care conditions. This is evidenced by the success achieved in relation to children's nutritional status and mortality among breast-fed babies, as demonstrated by specific indicators, greater opportunities for health care choices (patients whose health problems cannot be treated in their own countries can explore the international health care available and choose the most convenient option), an increase in the external aid of developed countries as evidenced by the MDGs in the case of malaria, tuberculosis and HIV (the containment of the spread of AIDS in many countries through the implementation of

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prevention programmes) [7], and the fact that new information and communication technologies enable health professionals from anywhere in the world to access scientific evidence and improve their clinical decisions [6].

Concerning the objective of this chapter, however, the relationhip established between globalization and HIV is robust. So much so that HIV, along with other diseases such as tuberculosis and malaria, is presently termed a "global disease". To a large extent, this is the result of the movement of goods and people, which has also increased the likelihood of diseases spreading worldwide. Diseases, like goods and people, also commute across oceans and borders. For this reason, one of the main concerns of international public health is the speed, as well as the high rates, of the worldwide spread of highly contagious diseases, as illustrated recently by the alarm triggered concerning Ebola infection.

HIV is a clear exponent of transnationalization and constitutes a global epidemic that now poses one of the major threats to global health. Such has been the scope of the pandemic and the resulting consequences that today, it can be affirmed that HIV represents one of the most severe public health epidemics ever suffered by humanity. Therefore, considering the gravity of the situation, the international organism UNAIDS was created to respond to this issue.

According to an UNAIDS 2013 report, it is estimated that on a global scale, 35.3 million people were living with HIV in 2012, an increase compared to previous years [8]. This is largely due to greater accessibility to treatment. In other words, there are progressively more people in the world receiving antiretroviral therapy, which raises their life expectancy. The distribution according to population group is 31.8 million adults and 3.2 million children [8]; 2.3 million new cases of HIV infection were reported throughout the world in 2013, compared to the 3.4 million cases recorded in 2001 [8]. Consequently, these figures show that there has been a decline of approximately 33%. In the case of new infections HIV in children, 240 000 children worldwide (210 00-280 000) contracted HIV in 2013, compared to 580 000 (530 000-640 000) in 2001, signifying a decrease of 58% [8]. Similarly, the number of deaths from AIDS has also declined: 1.6 million deaths were recorded in 2012, compared to 2.3 million recorded in 2005. Specifically, 1.3 million deaths occurred among adults and 190 000 among children.

HIV indicators	2002	2012
People living with HIV (Total)	30.7 million	35.3 million
New HIV infections (Total)	3.3 million	2.3 million
AIDS-related deaths	2.1 million	1.6 million
People accessing treatment	There is no data available	12.9 million

Source: UNAIDS, 2013

Table 1. Structural indicators of HIV

Despite the progress that has been made, epidemiological data continues to show alarming figures, as reflected in Table 1. As such, there remain major obstacles in the eradication of the pandemic. According to UNAIDS' most recent report (2013), some of these challenges are [8]:

1. Reducing the sexual transmission of HIV in African countries where a decline in the use of the masculine condom has been detected.
2. Reducing HIV transmission among people who inject drugs, since data shows this remains highly prevalent, whereas HIV prevention coverage remains low.
3. Reducing new infections in children, as well as maternal mortality during pregnancy.
4. Improving the availability of and accessibility to antiretroviral therapy in low and middle-income countries.
5. Reducing the number of tuberculosis-related deaths in HIV patients.
6. Eliminating stigma, discrimination and coercive laws and practices in relation to HIV.
7. Eliminating gender inequalities, abuse and violence that cause the feminization of HIV.
8. The integration of people affected by HIV.
9. The overall lack of resources in the fight against AIDS.

HIV constitutes a clear example of social inequality in relation to health. In overall terms, the highest prevalence of the pandemic occurs in countries with low human development indicators. This increases social injustice and accentuates existing inequalities in these countries. According a UNAIDS report (2013), some of the countries that present higher prevalence rates with regard to global prevalence are [8]:

Country/ Region[1]	Prevalence of HIV (2012)
Swaziland	28.3%
Lesotho	24.7%
Botswana	24.4%
South Africa	18.4%
Zimbabwe	15.6%
Namibia	15.2%
Mozambique	12.9%
Malawi	11.4%
Equatorial Guinea	9.7%
North America	0.8%
Canada	0.3%
Western and Central Europe	0.2%

Source: UNAID, 2013

[1]Table 2 shows the existing discrepancies in the pandemic's global distribution; some countries show a higher HIV prevalence, according to a 2013 sample, while other continental regions show lower levels of prevalence.

Table 2. Prevalence rate of HIV infection in adults

Similarly, the overall distribution of AIDS-related deaths shows that the greatest incidence occurs in countries with low and moderate development rates: Nigeria (13%), South Africa

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(13%), India (8%), Mozambique (5%), United Republic of Tanzania (5%), Zimbabwe (4%), Uganda (4%), Kenya (4%), Malawi (3), Ethiopia (3%), China (2%), Russian Federation (2%), Democratic Republic of the Congo (2%) and Indonesia (2%)[8]. In the aforementioned countries, the epidemic represents a major public health issue. Not only is it a medical and health care issue, but it also constitutes one of the major obstacles to economic and social development [9]. For example, the high percentage of adult AIDS-related deaths results in the loss of the youngest and most productive individuals in a society, who are vital to economic development. Economic productivity also decreases, because AIDS sufferers and their caregivers stop working. Additionally, the educational system in these countries is affected by the percentage of teachers who die from AIDS, which means the loss of a significant part of the most educated population. Furthermore, the health care expenditure generated by providing health care services for people living with HIV and AIDS entails budgetary restrictions within the public sector. This constrains investments in other sectors aimed at promoting social and economic development. Finally, the scope of the epidemic in these countries is increasing, deepening poverty and existing social inequalities, and consequently inverting the human development trend. The HIV/AIDS epidemic has therefore become a priority for public policies in these countries. As a result, the response to HIV/AIDS and the fight against poverty has become the same battle [10]. For this reason, the elimination of HIV/AIDS has been established as a Millennium Goal, the sixth MDG [11], specifying the need to: "Halt and begin to reverse the spread of HIV/AIDS by 2015". Thus, the inclusion of HIV as a Millennium Goal evidences the global acknowledgement of the destructive and generalized effects of HIV/AIDS, as well as the belief that it is possible to overcome the situation by means of greater and more intensive national and international action, as well as the active will to do so.

3. Why is a sociological perspective of the HIV pandemic pertinent?

> "Health sociology is no longer, nor should [it] be, the simple contribution of techniques to the health care service but, on the contrary, should mean methodological independence [for dealing] with health from an interdisciplinary viewpoint, in which the biomedical aspect is only an additional component, however important it may be".[1]

Currently, it is widely recognized that the study of HIV constitutes a complex social phenomenon in which there is an interrelation between multiple social, economic, political, cultural and environmental factors in those communities where the pandemic develops and spreads. For instance, although HIV is a chronic disease in some European countries, in some African countries it is a deadly disease. Therefore, insofar as the epidemic influences the lifestyles, practices and subjectivities of a population, it is necessary to study it by utilizing tools that provide a more qualitative and in-depth knowledge of the phenomenon. Consequently, social sciences have begun to study the complex connections established in relation to the HIV phenomenon with the aim of providing knowledge for its understanding and comprehension.

1 Cited in: Donati P. Sociology of health. Madrid: Díaz de Santos; 1994.

However, despite existing evidence, the epidemiological method has been the benchmark for most of the approaches in the study of issues concerning public health in general and HIV in particular [10]. In this respect, it is worth noting that, currently, the epidemiological method cannot cope with the complexity of the HIV phenomenon on its own. Therefore, there is a need for HIV to be studied by different disciplines in order to address the complexity of the problem. For instance, the positivist method involves the limitation of not being able to grasp the qualitative aspects of health and disease. Thus, neither the subjective aspects of the disease nor the cultural factors influencing the HIV epidemic are present in epidemiological studies. In this sense, there is a need to generate qualitative information to help guide the design of prevention policies, particularly in regions heavily affected by the epidemic, such as African countries.

Social sciences provide a wide range of research theories and methodologies that can be extremely useful for studying HIV in general and in particular, its prevention and treatment. The sociological discipline, insofar as it seeks to explain and understand collective behaviour within a social context, the meanings of actions and the multicausality of phenomena, constitutes an essential tool in the construction of knowledge for an in-depth understanding of the HIV pandemic. Therefore, sociological theories constitute fruitful ground for investigating health and disease within the current context, as will be discussed throughout this chapter.

Health sociology, as a discipline, is a pertinent tool for the study of HIV. One of the reasons for the emergence of this discipline is the crisis of medicine, not as a science, but as a model of social practice [12]. One of the basic premises on which sociology is based is the need to focus on the analysis of health and not of disease, as opposed to the biomedical model that has primarily focused on disease. Such a fundamental purpose is in accordance with the need for placing greater emphasis on HIV prevention rather than treatment, in order to eradicate the pandemic. Therefore, assumptions that involve focusing on health from a sociological perspective constitute basic assumptions for prevention when applied to the field of HIV [13]:

- Preventative action holds keeping people healthy as a central objective and is based on actively guiding willingness and ability, considering health as a process and not as a state; emphasizing the dynamic role of the subject as a pole of active reciprocity in respect of medical and health care institutions and roles.
- To expect a permanent engagement with lifestyle changes focused on health, not only on behalf of the individual, but also on behalf of the social and health care system; planning and programming to prevent the disease both at an individual and collective level.
- To expect health to be promoted and safeguarded by all social actors, firstly, by all individuals, and in all cases, not wholly delegated to specific specialized places and centres.

Below, Table 3 shows some aspects that are likely to be investigated from a sociological perspective:

As will be discussed below, the different theoretical contributions of sociology will enable public health to approach health issues from a wider perspective, providing pertinent tools

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HIV objective issues	Theories and approaches
Perceptions and social representations of HIV	Phenomenology
Reasons for non- adherence to antiretroviral therapy	Ethnomethodology
Professional-patient relationships	Symbolic interactionism
Itineraries and satisfaction with HIV care	Phenomenology
Reasons for the adoption of preventive practices	Ethnomethodology
Stigma and HIV	Symbolic interactionism

Table 3. HIV objectives and sociological theories

for designing effective action in the fight against HIV. Additionally, sociology provides a multidimensional perspective for the study of behaviour towards HIV, the social roles that are played in professional-patient interaction, as well as the role of health care institutions and the social networks that influence the prevention of HIV. Finally, theoretical contributions of sociology are also relevant for designing and implementing health promotion programmes in relation to HIV.

4. Sociological approach to HIV research

Among the multiple sociological theories that offer a suitable approach for the study of HIV prevention, three relevant theories will be outlined: symbolic interactionism theory, ethnomethodology and phenomenological sociology. All of these are essential analytical tools for further exploring the above-mentioned aspects.

4.1. Symbolic interactionism theory

This theory focuses on explaining how people create their own identity and define themselves through their social experiences, that is, through their interaction with other people. Society is understood as a result of everyday, face-to-face, interaction among people. Through this interaction, people define and give meaning to the social world in which they live [14].

Symbolic interactionism is based on multiple premises. The most relevant and useful scenarios [15] for the study of HIV are: 1. Human beings react in one way or another depending on their perception of the object, person or situation they face, that is, the meaning they prescribe to a situation. 2. The individual (subject) adopts an active role in creating meanings. 3. Things do not have an inherent meaning; the meaning of things arises or emerges as a consequence of the social interaction established between people. 4. Meanings are handled in and modified through an interpretative process carried out by the person. 5. Common meanings make communication between human beings possible.

In summary, according to this theory, social reality is symbolically created during the course of social interaction and is therefore subject to change. Human behaviour is social and is based

on communication; therefore, people create and interpret social situations and their meanings during this communicative process. It is during the course of social interaction that objects gain meaning for the person or persons. These social meanings are created and modified during the dialogue of social interation.

Thus, the symbolic interactionist perspective is especially useful in the construction of behaviour, as it gives a primary role to the concept of the interaction that occurs between the members of a social group. Furthermore, "human beings interpret or define the actions of others, without being limited to simply reacting to them. Their response is not directly elaborated as a consequence of the actions of others, but is based on the meaning they give to such actions" [15]. Therefore, in relation to health and disease, and the prevention of HIV, this theory constitutes an important theoretical perspective for studying and explaining the social conduct of people and groups of people who interact with each other on the basis of sharing symbolic meanings. In the field study of HIV, symbolic interaction theory has been extensively applied [16]. This theory is useful for studying the stigma that exists among people living with HIV. Recently, it has been published a meta-analysis about ART non-adherence. The results of the study suggest that the existence of stigma is a factor of non-adherence [17]. This systematic review identified 34 studies that applied this theory. These studies indicated existing intrapersonal, interpersonal and structural barriers as a result of stigma as factors of non-adherence [17].

The process of social interaction constitutes a fundamental aspect in the study of the doctor-patient relationship. Since communication does not have a unidirectional character, the emission and reception of messages does not occur in a passive way. Such constant feedback creates a process that influences the way in which the disease and the person's subjective experience are created. This theory has been used to study the relationship between people infected with HIV and health professionals [18]. Recently, an interesting study conducted in Spanish health services analysed the relationship between people living with HIV and physicians as it concerns interventions developed within the areas of sexuality and safe sex [19].

Hence, symbolic interaction allows for a broader view of the approach to doctor-patient interaction, because it enables an understanding of the processes of social interaction that take place during the course of the relationship (doctor-patient). Subsequently, it also allows for an analysis of the role of the patient and health professionals in their encounters throughout the disease process. Furthermore, the communicative process that is established motivates the participation of other people, the family and the community. Therefore, the meanings and the subjective experiences of HIV-positive people are created during the social interaction process, not only with health professionals, but also with other individuals and groups with whom the HIV-positive person interact in normal everyday life. In this sense, studying doctor-patient interaction is useful for identifying the potential cultural barriers that can arise from this interaction. For instance, Spain recently conducted a research study, the objective of which was to understand and analyse the experience of immigrant HIV-positive women with health professionals and treatment services [20].

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The fundamental contribution of symbolic interaction to the field of social cognition is the consideration that mental processes are the product of symbolic interaction and not of internal individual processes [21]. Emotions are an example of mental processes that have been studied from a symbolic interaction approach, given that they are expressed in response to social relationships or situations, or both. Human interaction possibly plays the most important role in the activation and expression of emotions [14]. Thus, emotions are biological responses to social situations and the interaction between the people involved in such situations. From this perspective, health and disease are understood as human constructions perceived in a subjective manner by the population. It entails analysing peoples' everyday views of disease, the ideological connotations that health professionals attach to diseases, and the construction and application of medical knowledge [22]. Altogether, according to this theory, it is possible to analyse aspects that are relevant for the study of the HIV phenomenon, such as the different constructions created by people in their interaction with others, the meanings, perceptions, life experiences, beliefs, values in relation to HIV, guilt feelings for being HIV-positive, stigma, risk perception, as well as reasons for abandoning treatment.

4.2. Phenomenological sociology

The focus of analysing this theory is how meanings are created in the individual's consciousness. In other words, how life experiences influence and form part of the interrelationships established between two or more actors in everyday life and how these meanings can be revealed to an observer [23]. In the field of HIV research, this theory has been applied for studying the social about of the virus. The study of social representations of HIV has been extremely relevant to understanding the perceptions and meanings attached to the disease by the general population [24].

A series of key notions that summarize the author's thoughts and that constitute analytic tools for the study of the HIV phenomenon are described below:

- **Lifeworld (lebenswelt):** the lifeworld concept is an essential category for understanding the reality of the world of common-sense, as well as the reality of social action and interaction [25]. It refers to the intersubjective social world inhabited by the actor in daily life by applying a "natural attitude". This lifeworld is characterized as being an intersubjective and public world for the individual, and hence shared by and accessible to everyone. One of its main defining characteristics is that it is a pre-existing world. It is an intersubjective world that exists before being born and is given to the individual to experiment with and to interpret. In essence, it constitutes the horizon that embraces all possible ways of living and experiencing (where the fulfilment of humans in their human condition takes place) and of constructing a social life, transcending the vital experience of a particular actor. In the field of HIV research, this theory has been applied to the study and understanding of the different perceptions and meanings of the virus, as well as its influence on how people live and experience the disease [26].
- **Intersubjectivity:** this concept is essential for assimilating the mutual understanding that occurs between people during their interaction. It is defined by Alfred Schutz [27] as

"simultaneity... for it means that I grasp the subjectivity of the alter ego at the same time as I live in my own stream of consciousness... and this grasp [of] simultaneity of the other as well as his reciprocal grasp of me, makes possible 'our' being in the world together". The foundation of this concept is based on the social world, on the lifeworld; therefore, it is an intersubjective world, not a private world, one that is common to all. However, the intersubjective world is not only composed of subjective sensitivities, that is, what is received by the senses, but also of subjects' interpretations of those sensations. Therefore, it is based on how the subject interprets his/her surrounding world, as well as on the elements that condition this surrounding world and that make it possible to change or maintain the subject's interpretations and actions.

- **Typifications and recipes:** in the social world or lifeworld, people have a store of knowledge. A great part of this knowledge comprises what are known as "typifications" and "recipes". Typifications are schemes of reference, "knowledge that the world we live in is a world of more or less well circumscribed objects with more or less definite qualities, objects among which we move, which resist us and upon which we may act" [27]. Typifications exist in society; they are socially approved and are acquired through the socialization process and throughout the course of life. In contrast, recipes concern the knowledge used to understand or control aspects of experience, in other words, aspects that are related to situations and actions in the lifeworld, whereas typifications refer to the knowledge used to understand people or objects.

- **Meanings and motives:** action constitutes a human conduct consciously projected by the actor; hence, social action is that which involves the attitudes and actions of others, and is aimed at them during the course of the action. Meanings refer to the way in which actors determine what aspects of the social world are important to them, whereas motives attempt to reveal the reasons that explain the actions of the actors.

- **Roles:** defined as the typifications of what actors are expected to do in certain social situations. In the field of HIV research, the study of gender roles, both male and female, has been used to understand the reasons for why people maintain unsafe HIV behaviours [28-30].

- **Reification:** this concept is an analytical tool used by the authors from an integral perspective of the social world. Reification is the tendency to perceive human products "as if they were something other than human products – such as facts of nature, results of cosmic laws, or manifestations of divine will" [27].

- **Legitimizations:** these centre on the knowledge of reality in order to legitimize their existence.

In short, phenomenological sociology constitutes an important conceptual tool for approaching the study of HIV. This is the case because it is a theoretical perspective that permits for capturing the subjective meanings that people attach to their actions; additionally, it serves to describe and understand interpretations of meanings within the world, as well as for gaining a sense of the actions and interactions of people who are HIV-positive.

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4.3. Ethnomethodology

The primary objective of this theory is to analyse the individual's actions in daily life. Thus, it analyses how people define and construct, face-to-face (through interaction), each social situation. The traits that constitute social order are products of the activity itself. This order is "produced by the participants" and essentially carried out by means of verbalization [31]. Therefore, the study of language (the decoding of cultural meanings) acquires great importance. The study of social representations of HIV has been very relevant for understanding the perceptions and meanings related to HIV among the general population. For instance, a study recently conducted in South Africa analysed the discourse on risk perception that adolescents have in order to assess whether the contents of HIV prevention campaigns were suitable [32].

For an ethnomethodology, social reality is above all a reflexive and interactive activity that is socially constructed. According to this theoretical model, human society is the result of repeated interpretations that occur during the course of interaction. Ethnomethodologists' concern is that which Weber calls "significant behaviour" [21]. In order to understand this theoretical approach and its relevance for the study of the HIV phenomenon, it is necessary to know how it views social reality, the most significant premises in this context being the following five situations [33]:

1. Everybody, through our thoughts and actions, is immersed in a process of creating social reality. It is a process of which we are not aware.
2. The social construction of reality is constantly happening.
3. In their daily lives, people organize the world in coherent realities and this social reality depends on the participants' incessant reciprocal interaction and social construction of reality.
4. Given that this interactive and reflexive work constitutes reality, such a reality cannot be sustained without it. Therefore, each social reality is not a solid structure, but a very fragile creation that can break.
5. People live in diverse social worlds and they may move from one reality to another. Thus, behaviour that might be considered reprehensible in a certain social context may be acceptable in a different one.

Authors such as Caballero (1991) have described and analysed some basic concepts developed by ethnomethodologists, which constitute highly useful analytical tools for understanding and studying the HIV phenomenon [34], namely:

- **Explanations:** by means of the explanation process, people make sense of the world [35]. Explanations are used by actors to do things such as describing, analysing, criticizing and idealizing specific situations [36]. As such, this theory has been applied for identifying the reasons why people living with HIV leave treatment services [37]. Additionally, this theory has been applied for identifying the reasons why certain preventive practices, such as making an early diagnosis, are not acquired by certain populations [38-40].

- **Reflexive action and interaction:** the concept of reflexivity refers to how people who are interacting maintain the presumption that they are guided by a certain reality. In other words, humans interpret signals, words, gestures and information provided by other humans in a way that supports a certain view of reality. Even contradictory evidence is reflexively interpreted to maintain beliefs and knowledge.
- **Indexicality:** this term refers to phrases in which meaning varies depending on the context. It is therefore considered that all explanations must be interpreted within their specific context.

5. Research methodologies for studying the HIV pandemic

The sociological theories described in the previous section allow for investigating the phenomenon of HIV from its essential premise: HIV is a complex and dynamic social phenomenon that acquires different meanings depending on the social and cultural context of each society. These meanings, representations, perceptions, beliefs, values and life experiences will give meaning to and guide the behaviour and actions of people in relation to HIV. Furthermore, these different values and meanings influence the preventive practices that people adopt against HIV. Therefore, it is evidenced that there are qualitative aspects to the HIV phenomenon that also need to be known in order to prevent and eradicate the pandemic [10]. For this reason, most of the interventions being carried out in this field take the social dimension of HIV into consideration.

Therefore, sociological theories described in the previous section allow for grasping the qualitative aspects of HIV. However, the study of HIV using these sociological theories can only be developed from qualitative research strategies. In the scientific arena, the discipline that has traditionally investigated HIV has, however, been clinical epidemiology. For this reason, the research found in scientific literature is mostly prevalence and/or ecological studies. Consequently, in overall terms, there is a predominance of knowledge based on data that mainly describes how the epidemic is distributed among the population, depending on certain factors [10]. Furthermore, the qualitative factors that define the phenomenon of the HIV epidemic have evidenced the need for developing research methodologies that enable the study of the epidemic, transcending the simple observation of how it is quantitatively distributed within a certain population [10].

Using a qualitative methodology allows us to understand and comprehend the phenomenology of HIV from the perspective of the actors, as it focuses the way people interpret and give meaning to their experiences and the world in which they live. It approaches social reality from a holistic perspective, trying to explain, describe and understand people's discourses on a particular social phenomenon [41]. In brief, seeking the meaning of phenomena is the main function of "the so-called qualitative" [42].

A qualitative methodology is equipped with multiple data collection or production procedures that share common aspects, such as the understanding of social phenomena [43] or the

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centrality of discursive practices and discourse analysis [44]. However, each data collection method offers a particular type of information. Multiple procedures exist for collecting qualitative data. Some of the most representative techniques of the qualitative social research methodology perspective, which can be very useful for approaching the HIV phenomenon, are the following: qualitative interview, focus group, life history and participant observation. It is worth noting that, like the rest of the techniques for collecting and analyzing information on research, these techniques ensure the confidentiality and privacy of the respondents to the extent that the information is treated anonymously and not personalized. Such techniques are usually applied in cross-sectional studies.

5.1. The qualitative interview

The origin of qualitative interviews may be traced through the fields of anthropology, sociology, psychology and journalism. In the 19th and early 20th centuries, this approach began to be consciously applied in social research [45]. It is important to distinguish between the social research interview – in its different formats – and other types of interviews, such as those carried out by health professionals during the course of their duties. Although there are multiple differences, their objective – that is, the purpose of the social research interview – may be highlighted thus: "the research interview intends to construct [a] social sense of the individual's behaviour or of the behaviour of the individual's reference group, by gathering a set of personal data" [46].

Presenting a single concept of the qualitative interview is complicated, because both the conceptualization and the practice of the interview are determined by the different paradigmatic perspectives and positions adopted in relation to qualitative research. Therefore, the diversity of interview styles and manners is fairly heterogeneous. This heterogeneity causes some authors to talk about qualitative "interview families", as in the case of Herbert J. Rubin and Irene S. Rubin [47], who include in this category interviews that have a *semistructured* format (in reference to the focalized interviews of Merton and collaborators) and those that are *unstructured* (referring to the works of Douglas [45]. They also define a *combined modality*, present in many qualitative interviews, where there are "parts that are more structured and others that are less structured, however the balance between them varies" [45]. The different styles and forms of interviews determine if they are more or less structured. There is not only one way of interviewing a person; nonetheless, depending on the higher or lower level of flexibility of the guide, interviews will be more or less structured. They can thus be classified in the following way:

- **Structured interviews:** consist of providing structured questionnaires in which both the sequence and the formulation of the questions are predetermined.
- **Semistructured interviews:** as with the previous type, the questions are previously defined in an interview guide but their sequence, as well as their formulation, may vary depending on each interviewee. In other words, the researcher asks a series of questions (generally open at the beginning of the interview) that define the area of research, but he/she has the freedom to pursue ideas that might be relevant by asking new questions.

- **In-depth interviews:** also termed "open-ended interviews". These generally cover only one or two themes, but in greater depth. The rest of the questions that the researcher asks emerge gradually from the answers of the interviewee and focus fundamentally on the clarification of details, with the aim of delving deeper into the theme being studied.

In this sense and from a phenomenological perspective, supported by authors such as Taylor and Bogdan [43], the in-depth interview must be understood as "repeated face-to-face encounters between the researcher and informants directed toward understanding informants' perspectives on their lives, experiences or situations as expressed in their own words". According to these authors, in-depth interviews are appropriate in the following situations:

1. Where there is a wish to study events from the past, or it is not possible to have access to a particular type of setting and subsequently the settings, or the people, are not accessible in any other way.

2. The research depends on data from a wide range of people or settings.

3. When there are time constraints on research in comparison with other techniques, such as participant observation. Interviews permit for the more efficient use of time.

4. The researcher wishes to focus on the subjective human experience.

The qualitative interview is adequate for approaching people's experiences. It is a tool with a communicative character that attempts to capture the meanings mediated by the constructions that subjects build on the basis of their experience. Thus, in the case of HIV-positive people, as in the case of other social phenomena "contrasted with disease, which is a concept of biology –more specifically, of pathology– illness is a phenomenon which is apparent to the *individual* in terms of an altered state of perception of self" [41]. Therefore, the assessment carried out by a doctor is objective, differing from the subjective perspective of the ill person, because he/she is the one whose life is affected by HIV. For this reason, through the discourse that results from the interview, knowledge is generated about the life experiences, feelings, thoughts and perceptions of people that are HIV-positive. In addition, the meanings, norms and values created by people are binding on the members of a group, because they generate and condition people's behaviour. This is why the qualitative interview can help to explain the behaviour people demonstrate towards HIV and its treatments.

The qualitative interview is very useful in the field of studying the HIV phenomenon "when the hypothesis is a conflict between norms. On the one hand, there are norms which are dominant, referential, usually reproduced in discourses because they conform to what has been legitimated, what has to be said. On the other hand, there are norms in practice, reproduced in practice" [41], i.e., what is really done. Therefore, the relevance of its use in the prevention of HIV results from the knowledge provided when there is a divergence, or conflict, between social norms. For example, health professionals and the population in general point out the non-existence of stigma and discrimination of HIV-positive people in their discourses. However, they may be carrying out practices that lead to the stigmatization and discrimination against people affected by HIV. Furthermore, HIV-positive people may be acting in a way different to that which would normally be expected and might not be adopting preventive

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practices recommended by health services (legitimated discourse). For this reason, patients make evaluations on the basis of their own direct experience. In this sense, communicating to the ill person what he or she should do facing the illness in general and in particular towards its prevention is complex, because the patient is the one who is emotionally involved in a way that no else is. Therefore, the patient evaluates their condition based in their own experience. This self-evaluation is key to overcoming the illness, important in the adaption process to the illnessand in the preventive practices put in place. Consequently, the interview technique is highly relevant for identifying "above all, what is really done, or what is really thought, as the expression of following norms which deviate from the general norm" [41].

One advantage often emphasized when applying this qualitative technique is its suitability for ensuring the confidentiality of the serostatus interviewee, as opposed to other group qualitative techniques. Another advantage, because of the atmosphere of trust and privacy created between the interviewer and the interviewee, is the degree of freedom that respondents reach when responding to questions, which leads to expressing in confidence their experiences and opinions about HIV. On the other hand, a limitation that has been noted of this approach is that to achieve a degree of saturation sampling, a larger number of interviews must be conducted as opposed to other group qualitative techniques, resulting in research that is costly both in terms of time and financial budget.

5.2. Focus group

Research studies in the health care field primarily use focus groups and to a lesser extent, discussion groups. The focus group, also called the "group interview" [49], tends to be considered as "One specific technique within the broader category of group interviewing to collect qualitative data. The hallmark of focus groups is the explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group" [50].

The focus group is a technique that initially emerged in North American sociology as an extension of the focalized interview; coherently, its model is inquiry via questionnaire. The group modality reveals more nuances and more diverse responses than the individual interview, but always in a context of strong directivity in which a progressive logic prevails (step 1, step 2, etc., of the questionnaire). The group is constantly kept dependent on the moderator, who promotes the contrast between individuals rather than a group dynamic [49]. In this methodological practice, there is always a guide containing questions related to the research objective. The questions are aimed at the people who participate in the group, to be answered by the group. The researchers prefix the questions in the guide.

In its most extreme form, the focus group is a directive technique, because discussion among participants is non-existent if they simply respond to the moderator's questions one by one. However, in its more open form, there is the possibility of debate around explicit positions, in which the conversation is limited only to registering stated opinions [49]. It is also a structured technique, which uses the reflections of a group of people to reveal in-depth information on the theme being studied. It essentially consists of moderating a debate between a group of people who share certain experiences (possibly HIV), sociodemographic characteristics (age,

socioeconomic level, etc.), with the objective of discussing and reflecting on the different viewpoints of the theme. Creating a permissive ambiance is a key element for the discussion of these different points of view [49].

Quite often, focus groups and discussion groups are confused with one another. Although they have similarities, they also exhibit multiple differences. One difference worth highlighting is that the discussion group is designed to investigate the common areas of a group of people who, when placed in a discursive situation (conversation), tend to represent discourses that are more or less typical of the social groups to which they belong. However, in the group interview, a personal point of view prevails; hence, people listen as a group but answer as single interviewees [51]. The focus group is therefore a very useful qualitative technique for designing and assessing programmes and services. For example, for assessing user needs and satisfaction, identifying obstacles for implementation, developing educational materials, or assessing the quality of services. It is also useful for researching a certain phenomenon of interest, as in the case of HIV, especially when the aim is to understand attitudes and perceptions towards risk and behaviour, or to analyse cultural beliefs and values. Finally, the focus group is useful for the development of adequate measuring instruments aimed at the target population [52].

The focus group can be used as a research and assessment method, or as a complementary measure to other qualitative and quantitative methods, and is recommended when the objective is to learn about participants' experiences and perspectives. It is highly useful for studying what participants think of the group, but is especially valuable for finding out *why* they think the way they do [53]. Through this methodological practice, we may analyse the discourses produced by a group. This is useful for identifying user needs and satisfaction, and knowing the different points of view of key people regarding a theme as conflicting as the HIV phenomenon.

An advantage of this type of group technique is the fact that it allows for obtaining a large degree of information, as it reaches its saturation sampling level with fewer groups needing to be conducted. However, it has the disadvantage –as it happens in the case of the confidentiality of HIV serostatus– that it does not preserve discretion in front of the various components of the group.

5.3. Life history

Different social research techniques are included under the heading "biographic documents" (biographies, autobiographies, diaries, letters, life histories, etc.). Although these share common assumptions, their application is very different. The choice of one over another will depend on each approach's adequacy concerning the research objective. Among biographic documents, life history has been consolidated as one of the most efficient sources for obtaining data.

The aim of the life history is to collect a person's overall life history. The person involved is considered a key informant. Due to its scope, the life history is collected over an extended period of time. It tends to be exhaustive, using other testimonies or documents to corroborate

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or complete data. This technique is used when an exceptionally rich biographic narrative is available and the narrative corresponds to an extremely singular subject [54]. According to Sarabia, the term, "life histories" describes both stories of an entire lifetime and partial narratives related to certain life stages or biographic moments. Furthermore, it is worth noting that the term refers not only to the narrative, but also to all information gathered about the life under study (information from school stages, health care sources, etc.) and, obviously, to the analyses carried out by the researcher or researchers [55].

The use of life history as a research technique presents both advantages and limitations. According to Valles [45], some of the primary advantages that are worth noting are:

1. The retrospective and longitudinal character of the gathered data provides in-depth knowledge on the chronology, contexts of emergence and the development of social interaction, as well as the individual's points of view.
2. Having to conduct several interviews for each case or cases being studied elicits greater robustness and quality of data.
3. The biographic method, particularly the life history, has been recognized for its great capacity to implement the articulation of methods and techniques (methodological triangulation).
4. Emphasis on the objectives of the social experience as opposed to the objectivism of the experiment; the survey and systematic observation.

Similar to the individual interview, this qualitative data collection technique can prove to be extremely appropriate, due to the privacy guaranteed to individuals, which requires preserving confidentiality and anonymity, as is the case when involving HIV-positive people.

5.4. Observation

Observation is a common activity in everyday life. This type of common and generalized observation can be transformed into a powerful social research tool, and a scientific technique for data collection, when applied in the following ways:

1. Aiming and focusing observation at a particular and previously formulated research object.
2. Systematically planning the phases, aspects, settings and people to be observed.
3. Controlling and relating observation to social propositions and theories.
4. Subjecting observation to veracity, objectivity, reliability and precision controls [43].

Participant observation may be considered the prime example for illustrating that qualitative research methods are more akin to practices than techniques [42]. There are multiple definitions of participant observation. According to Taylor and Bogdan [43], the expression "participant observation" is used to define research that involves the social interaction between the researcher and the informants within the informants' context, a process during which data collection is conducted in a systematic and non-intrusive manner. Marshall and Rossman [56]

define it as "The systematic description of events, behaviours and artefacts in the social setting chosen for study" [56]. It therefore involves observing the context by means of integrating the researcher into the everyday life of the observed group, in a manner that is neither unstructured nor covert. Participant observation provides not only descriptions of people, events and interactions that occur between people, but also of the experience, life experiences and sensations of the researcher [44].

The primary use of participant observation is to be found in the study of that which falls relatively outside the norm: that which is still not understood, is incipient, relates to other cultures, half-hidden or clandestine groups, as well as that which tends to be confined to institutions (whole institutions, work centres, laboratories, etc.). In other words, in those places where what is normal is bracketed and where it is understood that things are socially different to what is considered either normal, or to what appears in the institutions' formal discourses [42]. Consequently, participant observation is especially useful for in-depth studies of the everyday life of organizations, institutions and social groups that occupy a peripheral space within society. In the area of health care, this means using it to study the everyday and organizational lives of health centres, specific professional associations, hospital wards, etc. [42]. Participant observation is adequate when seeking to reveal the practical rules of a community, group, organization or institution.

Participant observation is defined by the interaction between the observer and the observed, within the context of the observed, and therefore involves the importance of the community setting that is to be observed. Choosing the settings to be observed is of the utmost importance for the research, as not all settings allow for the presence of an observer, nor are they susceptible to being observed. The particular research determines the selection of the setting and the scenario that will be observed, and not the other way around [43].

Therefore, participant observation reveals the practical rules of people affected by HIV when in a group, of the associations of HIV-positive people, of health service organizations and of the exact representation of a given culture, among others. Furthermore, as well as bringing forth participants' discourses that are embedded in everyday practices, it enables the identification of discrepancies between discourse and behaviour. For instance, HIV-positive people undergoing antiretroviral treatment may say that they are following treatment when in fact, it is observed that treatment dropouts are frequent. Therefore, knowing the practical rules that condition the behaviour of people towards HIV is highly important for the development of intervention programmes aimed at the prevention of HIV. These programmes need to be adapted to the social and cultural rules that prevail in the different social and cultural contexts of the societies in which interventions will be undertaken.

6. Conclusions

As discussed above, HIV is a complex phenomenon in which many aspects (social, cultural, etc.), not only clinical and biological, are interrelated. Intervening factors in the HIV phenomenon include social, economic, political, cultural and environmental aspects. The HIV phe-

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nomenon interacts with lifestyles and practices, as well as with the subjectivities of the population in communities where it develops and spreads. Therefore, it is currently a fact that the epidemiological method is insufficient for providing holistic and hermeneutic knowledge on the issue. For this reason, a primary conclusion of this study is the need for applying other methodologies and theoretical tools to study the phenomenon with the aim of providing such knowledge. Furthermore, this knowledge is a key element for assuring efficient and effective HIV prevention policies and strategic planning. In this sense, sociology and in particular health sociology constitutes a pertinent conceptual and methodological tool for studying the HIV phenomenon in all its complexity. In this sense, it seeks to explain and understand the collective behaviour that occurs in a social context, the meanings of actions and the multicausality of phenomena.

The theories that have previously been explained are relevant methodological and theoretical tools for comprehending the complexity that defines HIV. Though these instruments differ, they do have certain common characteristics that should be taken into consideration. A common premise is: conceiving human action in terms of its intentionality, autonomy and reflexivity. All these characteristics share a subjective view of human behaviour, because they define its discourses. Consequently, the relevance and contribution of these theories to the study of health and disease, and specifically to the study of HIV, is now a fact. The advantages of this are multiple:

- Enabling the understanding of the health-disease-attention process and ultimately, the behaviour that results from the interaction between those involved in this process, as well as offering coherence to these conducts. In this sense, it reveals conducts towards both the diagnosis and the treatment of HIV.
- Knowing and understanding how individuals and groups participate in the construction of social representations of HIV.
- Knowing and analysing the social control mechanisms that arise in relation to people with HIV, such as stereotypes, prejudices, stigma and discrimination.
- Analysing the different meanings that exist in the construction of the HIV phenomenon; a construction that is built on perceptions, life experiences, images, ideas, representations and social control mechanisms. These meanings enable us to understand how people relate their way of thinking to their way of acting towards HIV.

These theories are relevant and pertinent for obtaining useful knowledge to guide the design of effective and efficient health promotion policies and strategies, specifically for the prevention of HIV, as they focus on the problem of how actors in different contexts create a view of reality. Finally, a series of methodological tools were discussed whose validity and pertinence for the study of HIV are currently beyond any doubt. This has been evidenced by multiple studies in the field of HIV prevention, which have been conducted using this qualitative methodology.

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